



EPILEPSY CHRONICLE

Epilepsy Care and Research Foundation

November, 2012

Issue 1, 2012

Editorial

Dear Friends

"Epilepsy Care and Research Foundation (ECRF)", a non-profit non-government organization, was established under the auspices of Triveni Devi Sureka Charitable Trust and is dedicated to the care of people with epilepsy. The aims of the foundation are to achieve holistic goals of providing best possible management options for epilepsy, to impart education and awareness on epilepsy and to remove stigmas and social rehabilitation for patients of epilepsy with special emphasis being laid in the rural areas of Rajasthan. The goals of ECRF are to help patients gain control of seizure and optimize their quality of life. The purpose of the Foundation is to address various issues faced by patients of epilepsy across all age-groups including children and their guardian, women and elderly patients who have been afflicted and ravaged by the prevalent misconceptions and phantasms about epilepsy. Free medical care including drugs to the poor, financial support to epileptic students and explorative research in neural dynamics of epilepsy are main hallmarks and attributes of ECRF. Monthly camps are organized by the foundation on a regular basis in the district of Churu, Rajasthan to realize the aims and goals so formulated. It is a step taken and an effort to educate, manage, rehabilitate and make the patients of epilepsy and their attendants look at life from a different perspective!

The present newsletter is an attempt to bring in awareness and impart education in the neurophysiological, neuropharmacological and epidemiological perspectives of epilepsy. The discourse details the aims and objectives of the foundation and various errands ECRF has undertaken inclusive of disseminating knowledge regarding various myths and facts related to epilepsy. The foundation celebrated the National Epilepsy Day on November 17, 2011 and has been organizing camps on a regular monthly basis and effort has been made to explore and evaluate the interesting finding and observations that were made in the epileptic patients who attended the camps so organized.



R. K. Sureka

Dr. R. K. Sureka
(Editor-in-Chief)

हमारा परिचय

भारतवर्ष की जनसंख्या 121 करोड़ है जिसमें से करीब 0.5 से 0.9 प्रतिशत जनसंख्या मिर्गी रोग से ग्रसित है। भारत की 70 प्रतिशत जनसंख्या गाँवों में रहती है व 70 प्रतिशत चिकित्सक शहरों में अपनी सेवाएँ देते हैं। न्यूरोलोजी विशेषज्ञ बड़े शहरों में ही उपलब्ध हैं। ग्रामीण हिस्सों में मिर्गी रोग के बारे में अनेक आशंकाएँ व गलतफहमियाँ हैं। इस उद्देश्य को ध्यान में रखते हुए त्रिवेणी देवी सुरेका चेरिटेबल ट्रस्ट एवं ऐपिलेप्सी केयर एण्ड रिसर्च फाउन्डेशन के प्रथम चेयरमैन स्व. श्री मूंगालाल सुरेका (रिटायर्ड आई.ए.एस.) ने 1994 में यह शिविर का आयोजन शुरू किया और अब यह लगातार 18 वर्षों से निःशुल्क मिर्गी निदान शिविर, रतन नगर, जिला चुरू, राजस्थान में प्रतिमाह प्रथम मंगलवार को आयोजित किया जा रहा है।



मुख्य उद्देश्य

- आने वाले सभी रोगियों की जाँच करना, मिर्गी रोगी को उचित निदान प्रदान करना।
- सभी रोगियों को सम्पूर्ण ईलाज निःशुल्क उपलब्ध कराना, जिसमें प्रतिमाह रोगियों को पूरे माह की दवाईयाँ निःशुल्क उपलब्ध करवाना।
- मिर्गी रोग के बारे में व्याप्त अनेक आशंकाओं व गलत अवधारणाओं को समाप्त करना, जिसके लिए समय-समय पर प्रचार सामग्री (पैम्फलेट, चार्ट, बैनर आदि), स्वास्थ्य प्रदर्शनी एवं वीडियो प्रदर्शनी व जनचेतना कार्यक्रमों का आयोजन किया जाता है।
- शिविर के तत्वावधान में स्थानीय एवं सुदूर कार्यरत चिकित्सकों के लिए समय-समय पर सतत् चिकित्सा कार्यक्रम आयोजित किये जाते हैं।
- इस शिविर में मिर्गी रोगियों के उचित ईलाज के लिए अनुसंधान किये जा रहे हैं।
- सुरक्षित गर्भावस्था एवं प्रसूति को सुनिश्चित करने के लिए इस शिविर में चिकित्सकों द्वारा मिर्गी रोग एवं सुरक्षित गर्भावस्था के बारे में जानकारी प्रदान की जाती है।
- गरीब मिर्गी रोगी बच्चों को पढ़ाई के लिए छात्रवृत्ति प्रदान की जाती है।
- मिर्गी रोगियों के पुनर्वास हेतु सम्पूर्ण प्रयास किये जाते हैं।



उपलब्धियाँ

मुख्य चिकित्सक एवं न्यूरोफिजिशियन डॉ. आर. के. सुरेका के अनुसार अब तक 212 शिविर हो चुके हैं। इस शिविर में करीब 4200 मिर्गी रोगी पंजीकृत हैं जो भारतवर्ष के विभिन्न राज्यों जैसे हरियाणा, पंजाब, दिल्ली, उत्तरप्रदेश, बिहार व बंगाल से उपचार लेने आते हैं। इस शिविर में सभी रोगियों की जाँच एवं निःशुल्क दवाईयाँ दी जाती हैं एवं 60 से 80 प्रतिशत रोगियों के मिर्गी के दौरे पूर्णतः नियंत्रण में हैं। इन शिविरों में कई अनुसंधान किये जा चुके हैं, जो कि विभिन्न जर्नल में प्रकाशित हुए हैं।

- Clinical profile and specturm of epilepsy - A Rural study in Rajasthan ; JAPI 1999.
- Knowledge , Attitude and practice of epilepsy in Rural North West India; Annals of IAN 2007.
- Prevalance of Epilepsy in Rural Rajasthan - A door to door survey; JAPI 2007.
- Rural Epilepsy Clinic; Rajasthan Medical Probe.
- Dermatoglyphic patterns in Epileptic patients ; JASI, 2012.

17 नवम्बर को हर वर्ष 'राष्ट्रीय मिर्गी दिवस' के उपलक्ष्य में प्रतिवर्ष जन-चेतना कार्यक्रम आयोजित किया जाता है एवं बच्चों के लिए चित्रकला प्रतियोगिता व अन्य कार्यक्रमों का आयोजन किया जाता है।

रोगियों एवं उनके परिजनों के लिए मिनरल वॉटर व निःशुल्क भोजन की व्यवस्था की जाती है।

Epilepsy Awareness Program 2011

The Jaipur Chapter

An epilepsy awareness programme was organized on 17th Nov, 2011 on the occasion of the National Epilepsy Day by Epilepsy Care Research Foundation at JMA Hall, SMS Medical College, Jaipur. The function was inaugurated by Chief Guest Dr. Ashok Panagariya (Professor Emeritus Neurology and member of State Planning Board (Health) and was attended by leading neurologists, epileptic patients, and relatives.

On this occasion, the Secretary of the Foundation and Professor of Neurology at SMS Medical College Dr. R. K. Sureka emphasized the need of awareness of epilepsy and the role of health education and removal of prevailing myths and beliefs about the disease in general masses. A poster depicting the causes, precipitating factors and the Do's and Don'ts was released by the Chief Guest Dr. Ashok Panagariya along with Dr. Subhash Nepalia Principal SMS Medical College. Also, a video prepared by Dr. Sureka in Hindi about epilepsy awareness was launched on YouTube and on website www.epilepsycrf.com. On this occasion students also took out a rally with awareness posters about Epilepsy and a message regarding misbeliefs was also relayed on FM 94.3.

The Ratan Nagar, Churu Chapter

Epilepsy Care and Research foundation is working for the welfare of epileptics in rural areas of Rajasthan since last 18 years. Professor Dr. R.K. Sureka, reports that this foundation is holding free monthly rural camps at Ratan Nagar, Churu in Rajasthan.

The **200th camp** was held on **8th November, 2011** at Ratan Nagar where **National Epilepsy Day** was celebrated. As reported by Dr R.K. Sureka, an **Exhibition** depicting the various facets of Epilepsy was organized and visited by residents of the village and about **590** patients and their relatives where people were educated about Do's and Don'ts. Similarly an audio visual film was also run for the Epileptics. A **painting competition** was also held for Epileptic children below 16 years of age and best five paintings were rewarded. The chief guest on this occasion was the M.L.A. Churu, Shri. Maqbool Mandelia who flagged the **march "Fight against Epilepsy"** in which about 50 school children participated and who carried the message of "Control Epilepsy, Fight against Epilepsy" to the masses.



Poster Release



Inauguration of Rally by Chief Guest



Painting Competition

Epilepsy Research Activities

According to the chief Neuro-Physician of ECRF, Professor (Dr.) R. K. Sureka about 212 free camps have been organized as per schedule at Ratan Nagar, Churu and around 4200 odd patients from across the nation namely, Haryana, Punjab, Delhi, Uttar Pradesh, Bihar and West Bengal have been registered in the camps as of this date. Free medicines and free investigations are carried out in these camps and about 60 to 80% of the patients have become seizure-free as a consequence of such a focussed and concerted effort! Besides imparting education, awareness and effective management to epilepsy patients, the camps give the team of Medical professionals the right impetus, data and ground work for exploratory research in field of various seizure disorders. The various research papers published under the able tutelage of Professor R. K. Sureka and his team are as follows :

Professor (Dr.) Sureka reported the **Clinical profile and spectrum of epilepsy in rural Rajasthan** in the *Journal of the Associations of Physicians of India* in 1999 (47, 608 – 610), wherein the side effects of anti-epileptic drugs (AED), role of education and the clinical profile of epilepsy in sample population and their attendants were evaluated for a period of one year. About 80% of the patients had generalized tonic and clonic seizures with a preponderance of male patients with the mean age of onset of seizure being 10 years. Around 70% of the patients could be fully controlled with pharmacotherapy and were seizure-free. It was concluded from the study that epileptic patients could be managed in the rural scenario without the need for sophisticated investigations.

The Prevalance of Epilepsy in Rural Rajasthan was a evaluated during the period of January 2005 to October 2005 as door to door survey [*Journal of the Associations of Physicians of India* in 2007 (55, 741)], the first of its kind done in Rajasthan, a total population of 1,72,442 was evaluated through the means of a well - structured and validated questionnaire. The prevalence rate of active epilepsy was reported as 3/1000, with the male: female ratio being 1.1:1. Generalized seizure was the most common (78%) type seizure that was observed in the survey. The survey was an effort to document the load and menace of epilepsy and was undertaken to sensitize the community and government to mobilize resources for the needful.

Another paper entitled **Knowledge, attitude and practices with regard to epilepsy in rural north-west India** was published in 2007 in *Annals of Indian Academy of Neurology* (10, 160 – 4). The prospective longitudinal study stretched through four years from 2000 to 2004 and it was observed that generalized seizures were the most common type (84%) of seizure that was reported followed by partial seizures (9.4%). The most common and effective AED used was phenytoin followed by phenobarbitone. Ayurvedic treatment was the most common alternative therapy used. Evil spirits were believed to be the cause of the disease by 26.4% of the patients in 2000, but with intervention and education the percentage declined to 11.2% in 2004. Faith in scientific and logical management of pharmacotherapy increased from 18% in 2000 to 59% in the year 2004 and polytherapy regimens (60%) in 2000 could be effectively converted into monotherapy regimen (45.6%) in 2004. The findings reiterated the fact that education, awareness and logical management of epilepsy can effectively remove the mis-concepts of epilepsy and make life better for the epileptic patients.

Professor (Dr.) Sureka and his team investigated the **Dermatoglyphic pattern in epileptic patients** and their interesting findings were published in 2012 in the *Journal of Anatomical Societies of India* (61, 26 – 29). Statistically significant difference could be appreciated in the dermatoglyphic traits of a – b ridge count, lateral deviation, c – line, palmar pattern and finger-tip pattern in patients of epilepsy as compared to that of the controls. The study further underscored the relevance of antenatal factors in the etio-pathogenesis of epilepsy and opened newer avenues for research and diagnosis.

गलत धारणाएं और सच्चाईयां

गलत धारणाएं	सच्चाईयां
मिर्गी छूट की बीमारी है।	मिर्गी की बीमारी एक व्यक्ति से दूसरे व्यक्ति तक नहीं फैलती है।
मिर्गी का दौरा पड़ने पर मरीज के हाथ में चाबी पकड़ाने या प्याज या गंदा जूता सुंघाकर, दौरे को बंद किया जा सकता है।	मिर्गी दौरा पड़ने प्राथमिक चिकित्सय उपचार उपलब्ध है।
मिर्गी के मरीज न तो शादी कर सकते हैं और न ही सामान्य बच्चे पैदा कर सकते हैं।	मिर्गी के मरीज एक सामान्य जीवन जी सकते हैं। शादी करते हैं और परिवार का पालन पोषण करते हैं।
मिर्गी एक तरह मानसिक बीमारी या फिर विकृति या फिर किसी बुरी आत्मा का साया है	मिर्गी एक अम्ब्रैला है जिसके अंतर्गत लगभग बीस प्रकार के मिर्गी विकार आते हैं, यह एक संचालनात्मक, शारीरिक समस्या है, मानसिक नहीं।
मिर्गी के दौरान आप अपनी जीभ भी निगल सकते हैं।	अपनी जीभ को निगल जाना शारीरिक रूप से असंभव है। मिर्गी के दौरान व्यक्ति के मुंह में कोई भी चीज जबरदस्ती न डालें।
मिर्गी ग्रस्त व्यक्ति विकलांग होते हैं और कोई काम नहीं कर सकते।	मिर्गी ग्रस्त व्यक्ति की तरह अकलमंद होते हैं और हर काम कर सकते हैं। मिर्गी से ग्रस्त महान हस्तियां : सुकरात, नेपोलियन बोनापाट, जॉंटी रोड्स मिर्गी के मरीजे।

मिर्गी का दौरा पड़ने पर

ऐसा करें	ऐसा न करें
न घबराएं, न ही डरें। शांति रखें। मरीज को खुद को चोट पहुंचाने से रोकें।	मरीज के मुंह में चम्मच या अन्य कोई चीज न डालें इससे सांस लेने में तकलीफ हो सकती है।
मरीज को जमीन पर गिरने से बचाएं। मरीज के शरीर पर मौजूद बेल्ट, टाई या अन्य चुस्त कपड़े अलग कर दें, चश्में उतार दें।	मरीज के शरीर में होने वाली ऐंठन या हलचल को रोकने की कोशिश न करें, इससे हड्डी टूटने का जोखिम हो सकता है।
सर के नीचे तकिया रख दें। मरीज के आसपास मौजूद तेज धार वाली या नुकीली चीजें अलग कर दें।	मरीज के आसपास भीड़ न लगाएं। मरीज के पूरी तरह होश में आने तक उसे कोई तरल पदार्थ न दें।
दौरा खत्म होने के बाद, मरीज को करवट के बल लिटा दें, ताकि सांस लेने में रूकावट न हो।	मरीज को शारीरिक रूप से पकड़ने की कोशिश न करें।
दौरा खत्म होने के बाद, मरीज को करवट के बल लिटा दें और मुंह से निकलने वाला झाग साफ कर दें। मरीज के साथ तब तक रहें , जब तक आपको विश्वास न हो जाए कि वह पूरी तरह ठीक है।	आम तौर पर चिकित्सय सहायकता की जरूरत नहीं पड़ती होती, आम तौर पर मिर्गी का दौरा 2 मिनट का होता है, जिसके बाद मरीज गहरी नींद सो जाता है।

गलत धारणाएं एव सच्चाईयां



भ्रान्ति

मिर्गी के रोगी को जूता सुंघाने से दौरा खत्म हो जाता है।

वास्तविकता

यह सब झुठ है, ऐसा कुछ भी नहीं होता।

भ्रान्ति

मिर्गी का रोग भूत-प्रेत व देवी देवताओं के प्रकोप से होता है।

वास्तविकता

मिर्गी का रोग मस्तिष्क का रोग है व भूत-प्रेत से इसका कोई सम्बन्ध नहीं है।



मिर्गी दौरे आने पर क्या करें

1



रोगी को तिरछा लिटा दें।

3



रोगी के मुंह में कुछ ना डाले।

2



रोगी के कपड़े ढीले कर दें।

4



रोगी से जबरदस्ती ना करें।

Epilepsy News

November 17 : The National Epilepsy Day

National Epilepsy Day is observed every year on November 17 to sensitize the public on various issues concerning and to address the need for people living with the condition to be given a fair opportunity in every aspect of life. The objective is to raise epilepsy to a new plane of acceptability in the public domain and social fabric and to increase public awareness of epilepsy as a universal and treatable brain disorder. In order to create awareness about epilepsy, the Epilepsy Care and Research Foundation (ECRF) is undertaking various initiatives. Some of the highlights of this awareness campaign include educating people about dos and don'ts and myths and facts of epilepsy, to ensure timely help to such patients, and special initiatives have been undertaken by the ECRF to fight the stigma associated with epilepsy, especially in rural India.

Purple Day – The Global Epilepsy Awareness

Epilepsy affects over 50 million people worldwide or approximately in 1 in 100 people, a figure that outnumbers multiple sclerosis, cerebral palsy, muscular dystrophy and Parkinson's disease combined. Purple Day, celebrated annually on March 26th, is an international grassroots effort dedicated to increasing awareness about epilepsy across the globe. Purple Day was founded in 2008 by a nine-year old girl, Cassidy Megan, of Nova Scotia of Canada with the help of the Epilepsy Association of Nova Scotia (EANS). The colour purple was chosen after the international colour for epilepsy, lavender. The lavender flower is often associated with solitude, which often is representative of the feelings of isolation many people affected by epilepsy and seizure disorders often feel. Purple Day India started in March 2011 by the Anita Kaufman Foundation.

Recent Advances in Epilepsy Care and Management

New Drug for Epilepsy

Epilepsy research has entered an exciting phase as recent advances have supplemented in vitro and in vivo electrophysiologic and phenotypic characterization. **Fycompa**, a selective, non-competitive AMPA receptor antagonist, has been approved by the US Food and Drug Administration (FDA) on October 22, 2012 as an epileptic drug that effectively controls epileptic seizures and has been found to be superior to its counterparts.

Vagus Nerve Stimulation

A new area that has garnered much attention of late is the use of brain stimulation to treat epilepsy. This area perhaps started with vagus nerve stimulation many years ago, but has recently grown rapidly to include brain targets. Vagus nerve stimulation (VNS) is designed to prevent seizures by sending regular, mild pulses of electrical energy through pacemaker to the brain via the vagus nerve.

MRI Guided Laser Therapy

Recent advances have shown that drug intractable epileptic seizures are amenable to MRI guided laser therapy, which can correct deep seated brain lesions. The laser ablation technique reduces the risk of complications of more invasive procedures like craniotomy.

Ketogenic Diet

Diet therapy in epilepsy in children has also been recently addressed. The ketogenic diet which is high in fat, low in carbohydrates and full of adequate proteins with omega 3 PUFA supplementation has been hypothesized to be effective in uncontrollable refractory seizures in children.

Dr. R. K. Sureka

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